





"Your twin daughters have an extremely rare, fatal disease called Niemann Pick Type C and there's nothing you can do for them". Those were the devastating words that Chris Hempel and her husband first heard in 2007. Rather than just give in to this fate, the Hempels are proactively engaging researchers to try to save Addi and Cassi's lives. This journey includes donating skin samples to cell banks so that researchers can create induced pluripotent stem (iPS) cells, a promising technology which may help undercover treatments for their daughters. In this video, Chris Hempel speaks to the CIRM Standards Working Group to present a patient advocate's perspective on the challenges of rare disease research. Hempel was introduced by CIRM Governing Board member, Sherry Lansing.

For more information about the Hempels and Niemann Pick Type C, visit: http://addiandcassi.com/

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